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Exploring what motivates and sustains support group engagement amongst young people with allergies: a qualitative study

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## **Abstract**

### **Background**

Positive self-care behaviours are more likely in young people who engage with allergy support groups, but reasons for this association are not well understood.

### **Objectives**

This study explored how and why young people engage with allergy support groups to identify what activities and resources are beneficial.

### **Methods**

In-depth, semi-structured interviews were conducted with young people aged 12-21 years who reported engaging with allergy support groups (in person or on-line). Interviews were audiotaped, transcribed verbatim and analysed using thematic content analysis.

### **Results**

The 21 participants had a range of allergies; initially most joined support groups on suggestion of their parent/carer although older participants sought groups independently. Feeling included and sharing experiences with people with similar problems/challenges were highly valued. Through membership, young people reported improved self-esteem and confidence in both managing their allergies and lives generally. Information, such as allergy alerts and hard-hitting video campaigns were reported to positively influence adherence to self-care behaviours such as carrying medication which led to sustained engagement. Participants wanted greater availability of allergy support groups, and higher profiles in healthcare and educational settings, as well as through social media.

### **Conclusions and clinical relevance**

Participants valued the psychological and practical support of networking with others with allergies, and described how membership improved their confidence. This study also provides insight into the ways support groups improve young people's adherence to medical advice and positive self-care behaviours; participants responded well to hard-hitting video campaigns which appeared to emphasise the severity and susceptibility of anaphylaxis. Participants identified the need for more active promotion of support groups amongst young people and their clinicians, as well as making them available in more localities.

## Introduction

Anaphylaxis can be fatal and a review of deaths highlighted that most occur in adolescence or young adulthood as a result of delayed or non-administration of adrenaline (1-4). A recent study, explored factors which affect adherence to positive self-care behaviours in adolescents with severe allergy (5). Adoption of positive self-care behaviours, such as avoiding known triggers and carrying emergency medication, including adrenaline auto-injectors (AAIs), were 2.5 times more likely when young people were engaged with an allergy or anaphylaxis support group (5). The National Institute for Health and Care Excellence (NICE) guideline on assessment and referral after emergency treatment for anaphylaxis recommends that information on patient support groups should be provided before discharge by an appropriate health care professional (6).

There is evidence from the adult literature that amongst those aged 18-30 years with type one diabetes, participation in a pilot support group led to improvements in diabetes self-care and better disease management as a result of individuals sharing experiences and how they overcame challenges (7). Furthermore, a qualitative study of adults aged 20-48 years found that the decision to engage with online support for food allergy was driven by the benefits of improved accessibility, social support and sharing of effective coping strategies (8).

However, empirical evidence in adolescents is lacking and whilst the association between engagement with support groups and positive self-care behaviours is suggestive of benefit, no research to date has explored what motivates young people with allergies to engage with support groups and what benefits they derive from engagement. This qualitative study was designed to explore why young people with allergies join support groups, what aspects of membership are perceived as helpful and how membership influences behaviour leading to sustained engagement. In addition, young people were asked to describe how support groups could improve and extend their activities to better meet young people's needs.

## Methods

### Recruitment and consent

The Brighton & Sussex Medical School Research Governance and Ethics Committee (BSMS RGEC) provided ethical approval (ref: 15/081/JON). Young people (aged between 12 and 21 years) with allergies who engaged with one or more allergy support groups were invited to participate. As some charitable organisations require a minimum age of 18 for membership, the inclusion criteria extended to those engaging with online support groups. Recruitment was through adverts in

newsletters, websites, and emails from allergy and anaphylaxis charities (such as The Anaphylaxis Campaign and Allergy UK), in addition to social media hosted support groups (such as “Nut free living”, “UK Nut Allergy Sufferers”, “UK Allergy Mums”). The advert explained the study and provided contact information for young people to request further information and express their interest. Information sheets and consent forms were emailed/posted to those expressing interest, for those under 16, parental consent was also obtained. All participants received a £10 voucher to thank them for their time.

## Interviews

Participants were offered face-to-face (depending on proximity to research team), telephone or Skype interviews. The interviewer (CJ) used a semi-structured topic guide which facilitated coverage of aspects of support whilst allowing participants to discuss issues of importance to them (Box 1). Recruitment continued until theoretical saturation was achieved, defined as no new themes emerging from three consecutive interviews. Interviews were recorded and transcribed verbatim.

## Data analysis

Thematic content analysis was performed on the interview transcripts based on the 14 stage structured approach described by Burnard (9). This involves appraising and coding the transcripts to initially identify as many categories as possible. To create broader categories, higher order headings and sub-headings are then generated. Interviews and analysis occurred concurrently so that emerging themes could be explored in subsequent interviews. Transcripts were analysed by two researchers (CJ and LS) independently, who then compared and discussed their findings to achieve consensus.

## Results

### Participant characteristics

Respondents (n=21) from England and Scotland ranged between 12-21 years (mean 17), 13 (62%) were female (Figure 1). All participants opted for telephone interviews. They experienced a range of allergies including food, venom and latex and all were prescribed AAIs. Of the 21 participants, all but two had experience of anaphylaxis. Participants reported engaging in one of 12 different in-person or online support groups and their experience of membership ranged from three months to 16 years. The majority of participants engaged in both face-to-face and online support, with online only support the next most popular form of engagement, involving following support groups on social media (Table 1). Four major themes with 11 subthemes were identified related to the factors which

motivated initial support group engagement and the benefits derived which led to sustained engagement (Box 2).

### **Drivers to encourage engagement with support groups**

#### ***Importance of recommendation from others***

The majority of respondents initially engaged with a support group on the suggestion of their parent. Interestingly, these participants tended to engage with both face-to-face and online groups. On only three occasions had the suggestion to join an allergy support group come from healthcare professionals managing the young person's allergy, suggesting that adherence to the guidelines which recommend patient groups is poor.

*"I think mum just mentioned it [the support group] and she asked me if I was open to go."*

(Female aged 15)

*"Well first my Mum was like: "Oh, you know this is the charity that deals with allergies". So I immediately thought "Oh. That is so cool - there is an actual charity that deals with it and stuff". And I was like: "Oh yeah sure, I might get involved with that.""* (Female aged 14)

*"I think the hospital might have ... oh yeah the hospital recommended it, because the dietician printed off a ... some information from their website about lupin and things."* (Female aged 15)

*"I did an internship last year for Severe Allergies, and the person who was in charge of me there [a doctor] actually recommended it. Because I hadn't heard of any of these groups on Facebook at all, but he had and he said "Why don't you have a look at these?""* (Female aged 21)

#### ***Self-motivation***

Conversely, older participants tended to have a shorter history of engaging with support groups reported being more self-motivated possibly precipitated by an increase in age-related independence or lack of recommendation from healthcare professionals.

*"I think I kind of found it myself, because I was very unfamiliar with this. So I just kind of googled 'allergy' you know, 'allergy help'. So I think it was probably more done on my behalf – but perhaps that is a reflection of my age at the time."* (Female aged 21)

*"I did some research and found it myself." (Female aged 20)*

*"No I did it off my own accord because I got ... there isn't much information out there. Unless you go looking for it the doctors don't tend to give you it. So I sort of started to look for it to find ways that I could look after myself better." (Female aged 21)*

### **Psychological and emotional benefits**

The emotional and psychological benefits of engaging with a support group were multifaceted and in some instance provided the initial motivation to engage with a group (in terms of the anticipated benefits such as hoping to gain friends with allergies) and also factored into young people's sustained engagement.

### **Feelings of inclusivity and shared experiences**

Young people of all ages reported that support groups reduced feelings of isolation with several participants mentioning no longer feelings not feeling alone with their allergy. They also appreciated that there was no need to explain to others what having an allergy was like, or the anxieties which can be synonymous with the condition. These shared experiences appeared to normalise their allergy. One young person reported feeling emotionally very low because of her allergy but was relatively new to support group; she reflected on how engaging with a support group earlier may have prevented this deterioration in her mental state.

*"I was kind of in my own world as lots of 6 year olds are. And I didn't really realise that there are other people with allergies, doing the same things as I was. So that was useful just to meet other people" (Male aged 19)*

*"It has just really helped to have someone to like ... who understands what you are sort of going through. And it is just really easy to talk to them about it" (Female aged 15)*

*"A lot of times you just feel the ignorance from other people and people think you are just being a fussy eater, when they don't understand the anxiety. You can just talk to them and they completely understand. And I think I just ... I felt quite relaxed... and not so alone with the allergy." (Female aged 20)*

*"I don't feel like I am alone or anything. I feel like ... I don't know, it is easier to make friends with them because they know what ... like we all go through the same things"* (Female aged 14)

*"I think the thought of going somewhere where you are all the same and you are all equal, is quite nice; because I met like a girl who is at my age, and we had so much in common. It was like ... you think sometimes you are the only one who understands, but there are so many other people who are out there"* (Female aged 12)

*"I think it might have stopped me going down-hill quite so quickly and getting quite that low, because the people in the groups do 'get it' and it does make you realise that you are not the only person. Yes you are 1-in-however-many, but you are not the only person in the UK who has got it."* (Female aged 21)

#### **Increased self-esteem and confidence**

Many young people reflected on how support groups had improved their feelings of self-esteem and confidence. This extended past obvious benefits of knowing more about their allergy and how to manage the disease and onto how to effectively communicate with adults and other general life skills.

*"I would be way more confident now than I would have been a couple of years ago, just because of those training EpiPens"* (Female aged 21)

*"I think it has changed my confidence a bit. Because I know there are other people like me."* (Female aged 12)

*"It made me feel more confident because I ... it would get to know, and like speak to adults, who are these big scary things (laughing) when I was a young kid"* (Male aged 19)

*"When I go away from home I know how to take care of myself, I feel like I know what I am doing"* (Male aged 15)



### **Reciprocal provision of reassurance**

Young people described being inspired and reassured by others in groups, this often related to older members who gave hope to those who thought that travelling or certain careers would not be a possibility for them because of their allergic status.

*"I found it quite inspiring I think... some of the places she had been to [older support group member with allergies] I never thought that I would be able to go to places. Like she was travelling around Asia I think and that is not something that you would imagine you would be able to do with nut allergies." (Female aged 15)*

*"But we have managed to get to know this person, in don't know how old this old lady is, like 80, and she is really, really cool. And she has loads of allergies and she comes and she did the job that I want to do" (Female aged 15)*

Young people also described how they were able to reciprocate by providing reassurance to others within the group, both to those with allergies and their parents/carers.

*"I guess you feel like you can give the younger children advice on how to keep themselves safe. And then you can also show the parents and the children that you will grow up and life will be ok." (Male aged 15)*

*"There were like five parents of little babies or toddlers who were there and they were really worried. "Oh my son is going to die!", "What shall I do?", "What shall I do?" And I think they were really reassured that I was there and I was still alive (chuckle) because they were like really worried. And they were like: "Wait!", "So you are like living with this"? And I was "Yeah it is not too hard when you know lots about it". I think they were really, really relieved that there was someone there who like had got through it and it wasn't that hard." (Female aged 12)*

### **Greater sense of empowerment and control over allergies**

Greater empowerment and control of their allergies was derived from support groups by having the opportunity to get accurate advice, discuss and rehearse potential solutions as well as explore the implications of what might happen if good self-care is not adopted.

*“Some people ... like don't let their kids like leave the house, pretty much. That is just ridiculous because you can't really have a life if they are just living in the house permanently. And they can't really grow up or anything. Or learn how to manage on their own, which is what they are going to have to do when they get older.”* (Male aged 16).

*“I like seeing the things that otherwise I might not see. It gives me some form of like a control.”* (Female aged 21)

*“So if you needed advice you could like talk to one of them or you could write down questions for the next time you meet. And then they will give you a good solution to it”* (Female aged 15)

*“When you go on the workshops they like teach you everything there is to know really about your allergies. Like what actually happens and ... err ... what is the best way to deal with it, and why you should carry medication? And it is not like to ruin your life or anything, it's just because if you don't have your medication and something goes wrong you die. There isn't like a second chance.”* (Male aged 16)

Young people also reported how a greater sense of empowerment and shock-tactics influenced and improved their self-care behaviours. Several recalled a video that emphasised the importance of carrying AAI. Young people also reflected on how support groups reinforced the severity of their condition (Table 2).

*“I watched one [video] where a girl didn't take it [AAI] out because she decided to take lipstick out instead. And obviously a boy wouldn't do that but ... she kissed someone, or something that had eaten peanuts, and it shows you that it can happen if you don't take it out and you swap it for something else, just 'cos you want that instead in your bag.... you should always take it out. Even if you wanted to take something else it is probably more important”* (Male aged 14)

## **Practical benefits**

### ***Provision of important information***

Support groups were considered a useful source of information (for example fact sheets, tips on effective communication about allergies in food outlets and ways to pose questions to experts) (Table 3). This advice was often seen to be more comprehensive and holistic than the guidance provided by the health care team managing the young person's allergy.

*"I think they do a very good job with the information side of what is an allergy and what foods and things are like included in the allergy, like the fact sheet" (Male aged 19)*

*"They have given me sort of like information stuff of what my allergens can be included in or how to deal with it or recommendations for restaurants or things" (Female aged 15)*

*"They actually recommended that we like spoke to the restaurant beforehand. Or sometimes you can take your own like food. Like I went to Pizza Express once and... I took my own pizza base and they were ok with that. I think I got recommended that by the group." (Female aged 15)*

*"I think it gives me the knowledge of what I need-should be doing, probably better than the healthcare team that saw me initially... Once I was diagnosed I wasn't really told again by the healthcare team, like what I should be doing. So that was more from the charity side that I got that knowledge" (Male aged 19)*

### **Convenience and accessibility of online information**

Young people appreciated the food alerts and up-to-date information posted on social media by allergy charities, it increased their awareness of changes to ingredients and new developments in research. Online access was also seen by many as enabling a useful forum for discussion between scheduled physical support group meetings.

*"Their Facebook page sort of shows you new and interesting articles about how allergies are being handled in different situations or news things on different developments and stuff. So it is like a way to keep up with everything that is happening and how it might affect you and your friends and your family and stuff like that" (Female age 15)*

*"The texts are really, really helpful because if you have bought something and you think it is fine, I think you are aware that you can't eat it, because otherwise you will have an allergic reaction, if you are not aware of it." (Female aged 12)*

*"Lot of young people use social media, and that would be a really good way to like talk to other people with allergies on social media like on a regular basis" (Male aged 12)*

However, social media was not universally favoured, with some challenging the extent to which some engage in online discussion and the accuracy of the information shared.

"I don't think that social media would be as good for young people ...I couldn't see people commenting and engaging in conversation. But I think the ones where you actually meet face-to-face are really helpful." (Female aged 15)

"Sometimes on social media things get a bit sort of twisted, [face to face] you would be able to get it straight from the person who knows what they are talking about, rather than it twisted down the chain." (Female aged 21)

Another challenge related to the lack of anonymity available when using social media:

"I think young people don't particularly want to be seen as part of a support groups." (Female aged 15)

"When you like a page and it comes up and all your friends can see it... maybe it would be better if... you could be part of it without anyone else knowing." (Female aged 15)

### **Increasing opportunities for engagement**

#### ***Increased awareness***

Awareness of allergy support groups was perceived to be inadequate both in the health care domain and more widely. A variety of suggestions were offered to promote membership, particularly advertising using media frequently accessed by young people (Table 4).

*"I think there needs to be a bit more awareness – so like more leaflets. And maybe adverts on TV."* (Female aged 12)

*"Maybe [promoting in] doctors surgeries because you don't usually see it ... well I have never seen anything like that in doctors' surgeries. Maybe schools and stuff like that."* (Female aged 21)

*I have never been sort of given a list to say 'you can join these groups' or 'here is some information to help'.* (Female aged 21)

*“And you have got to really dig deep to find it [a support group]. But it would be nice for it to be promoted more – or posted or things like that. Maybe in schools as well – I think that would be cool.” (Female aged 20)*

*“I wasn’t really aware. Ads online are probably the best – maybe like assemblies in school and stuff.” (Male aged 15)*

### **Greater geographic distribution of groups**

More opportunities for interaction were wanted; it was envisaged this could be achieved by the creation of more and geographically dispersed support groups together with the introduction of virtual interaction between scheduled group meetings. Male participants were particularly keen for support groups to offer more opportunities for fun or social outings.

*“To have more like local ones, because several people live in like ... up north, and they have to come down to London and sometimes it is a big journey” (Female aged 15)*

*“Maybe if they did have like activities – like events or trips. Like instead of being like just focussed about allergies, it could like be a place where all of the young people with allergies could kind of hang-out, a bit like a youth club or something.” (Male aged 14)*

*“So maybe a camp or something or outdoor activity: maybe even like a chat for people with allergies.” (Male aged 12)*

*“I think maybe if there could be like video chats. Maybe the Admin could go on and like ... like have video chats with us and like ... for everyone ... instead of like you having to go and meet up with someone physically, you could have like a group Skype session or something.” (Female aged 20)*

### **Age and experience related considerations**

Participants expressed concern that the age limits imposed by some social media sites and allergy support groups may inhibit membership and access to resources.

*“I think a problem that I saw with having an age limit younger than 18 was you have to pay to be a member. And I don’t think it’s so comfortable for people to be charging kids who aren’t earning any money, to be part of a support network like that. So I think the Facebook – I think it needs to be like two separate kind of things”* (Male aged 19)

*“And I always got really annoyed, because I was like “I really want to go”, “I really want to learn more”, “I want to know more about my condition”... but like they keep rejecting me because I wasn’t old enough.”* (Female aged 12)

Participants also felt that support group meetings for those with allergies should be separate from those for the parent or carers of someone with allergies, as the experiences and needs of the two groups differed. Young people spoke of greater benefits of joining a support group soon after diagnosis as they felt this improved how they managed their allergies. It was acknowledged that greater adjustment in lifestyle is needed if the allergy is developed later in childhood (Table 5).

*“They should do workshops where it is just adults and children. Because then the adults could talk about stuff that they don’t want to talk about in front of the children. And we can talk about what we don’t want to talk about in front of the adults, and like share stuff in common. Because some of the adults didn’t have allergies, their children did. So I think the children can talk about their allergies and what they have in common, and the adults can talk about what they have in common. Like the struggles that the adults have with children with anaphylaxis.”* (Female aged 12)

*“I think it was better with the ... just young people: not like parents butting in almost. I think it was better that it was just young people.”* (Female aged 15)

*“If you are not sure about anything what to do or you have just got it, or like you have like you have just started senior school and you have got it – because I know that they are like the hardest. Because you have lived all of your life and then you have just got something new and then you don’t know what to do.”* (Female aged 12)

## Discussion

The most frequent explanation for young people's initial motivation to engage with support groups was based on parental/carer recommendation. Engagement with support groups led to many benefits such as the ability to share experiences with people in similar situations which boosted their feelings of inclusivity and reduced feelings of isolation. Young people also described feeling more confident, empowered and competent, both in managing their allergies and in the general activities of life. Competence was generated through multiple factors; observing role models, the reinforcement of positive self-care behaviours, such as carrying emergency medication or negotiating an allergen free meal outside of the home, as well as receiving food alerts and practical advice on hidden/changed ingredients. Young people also seemed to benefit from support groups by both receiving support and also being able to provide reassurance to other members, or to parents/carers. These benefits led to continued engagement with support groups, with half of participants engaging for at least five years.

Our findings are consistent with studies amongst young people with diabetes and disability which describe how membership of support groups enabled opportunities for bonding with others similar to themselves, and how this increased a sense of belonging (7,10). In studies of adults' with a wide variety of conditions including allergy, cancer, stroke, diabetes, and physical disabilities, benefits of patient groups are also consistent with our findings suggesting that irrespective of the underlying condition or age, support groups appear to promote a sense of community, acceptance and emotional benefit, increased self-confidence and a decrease in isolation (11-14). Previous research has found that supportive networks lead to decreased engagement in risky behaviours, increased knowledge regarding management and an increase in treatment adherence and positive behaviours (7,8,10,15,16). Furthermore, the bonds that are formed within support groups between young people can also lead to positive social relationships which in turn, strengthen positive health care behaviours (17).

Previous research has identified that young people who engage with support groups are three times more likely to adhere to positive self-care behaviours (5). Participants reflected on how their self-care behaviours might be affected by support group engagement. Interestingly participants described how a hard-hitting video launched by The Anaphylaxis Campaign depicting a girl who decides to go out without her AAI and experiences anaphylaxis after kissing a boy, in addition to other negative experiences shared on social media, scared them into adhering to positive self-care. These type of approaches, often termed "fear appeals", are described as a "persuasive form of

communication that attempts to arouse fear in order to promote precautionary motivation and self-protection" (18,19). There has been long-standing debate over the effectiveness of fear appeals but a recent meta-analysis found evidence of effectiveness in influencing attitudes, intentions and behaviours. The largest effects are seen in females and when the message focusses on the severity and susceptibility of a particular situation and action (20). With this reassuring evidence, there is potential for allergy groups to utilise fear appeals more when designing future campaigns.

This study is, as far as we are aware, the first to explore the experience of support groups for young people with allergies. Participants generated rich data. Participants had a variety of food and non-food allergies, belonged to different support groups in different parts of the UK. This study would be categorised as a qualitative study that has high information power because it has a narrow aim, high specificity (all respondents were current members of allergy support groups) and focused dialogue (21). We acknowledge that our participants volunteered for interview, and thus they may have more positive experiences or derived greater benefit from their support group than those who declined. Future research is needed to explore the experiences of young people who do not belong to support groups and the reasons for this choice. Whilst our study provides greater understanding of the perceived benefits of membership, causation cannot be assumed. It may be that a young person's motivation to join a support group is also instrumental in their decision to engage in positive self-care behaviours. The only way to establish the true effectiveness of membership would be an interventional study with multi-method evaluation.

Surprisingly, only three young people had been recommended to seek the support of an allergy group by the healthcare professional managing their allergies. This indicates a need for patient organisations to work more closely with healthcare professionals to familiarise them with the additional activities, resources and support they can offer to patients. National guidelines should also recommend engaging with support groups, preferably earlier than on discharge from emergency treatment (6). Healthcare professionals could signpost patients to these groups, mention them in clinical letters copied to the patients and display contact details in waiting rooms. Other outreach for patient organisations could be via social media, which also could be used to enable members' discussions. This is a low cost option but care would have to be taken to monitor the accuracy of information and member anonymity. As many young people with allergy and asthma, also enjoy support derived through face-to-face interactions and social events (22,23), it would be desirable if support groups could be established in many more locations. As groups are largely



dependent on volunteers, such developments may not be so readily achieved, but the patient organisations can promote support by providing training and mentorship of group leaders.

Engagement with allergy support groups offers psychological benefits (such as decreased isolation, increased confidence and an appreciation of sharing experiences) as well as practical advice on managing allergies. Young people respond well to hard-hitting campaigns launched by some allergy charities, possibly by increasing their feelings of the severity and susceptibility, which appears to reinforce positive self-care behaviours (such as carrying emergency medication). There is a need to improve the promotion of support groups amongst young people with allergy and their clinicians given the relatively low-level of recommendations from health care professionals.

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Box 1. Example questions from semi-structured topic guide

How and when did you first hear about allergy support groups?

Why did you join/engage with a group at that time?

What is your experience of allergy support groups?

What do you get from engaging with a support group?

Thinking about all the things which are important to you in a support group, if you were to design your own support group, what would this look and feel like? What features and characteristics would you include?

Box 2. Major headings and right hand column subthemes on what motivates and sustains young people's engagement with allergy support groups

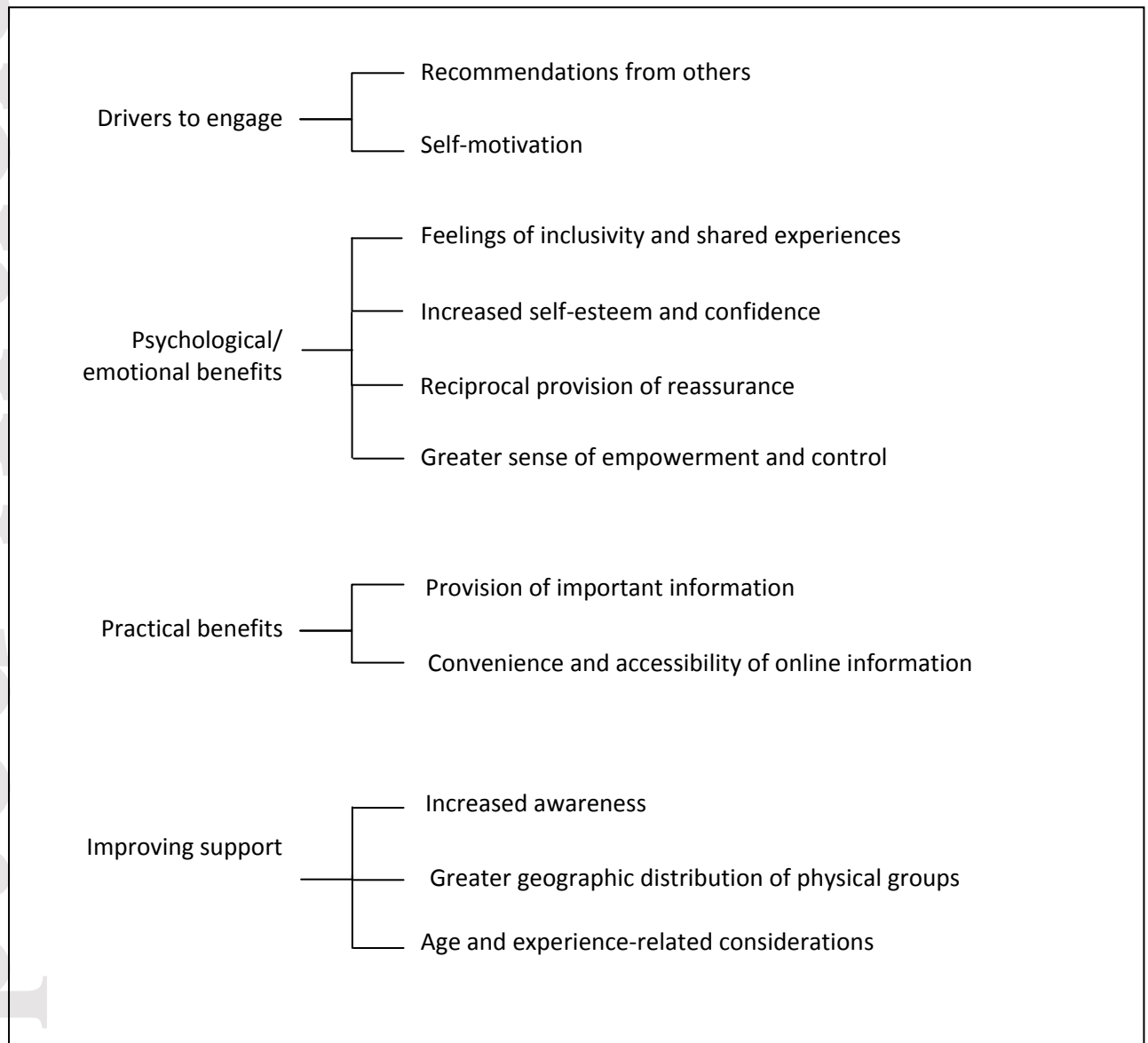


Table 1. Participant demographic and clinical characteristics

Age	Gender	Duration of engagement (years)	Allergens (as reported by young person)	Experience of anaphylaxis	Experience of support
14	F	10	Nuts (now desensitized to tree nuts), kiwi	Yes	Face-to-face, online
15	F	2	Nuts, dairy, intolerant to wheat, soya and gluten	No	Face-to-face, online
15	F	1	Nuts, peanuts, lupin, legumes	No	Face-to-face, online
16	M	16	All nuts, sesame, lupin	Yes	Face-to-face, online
18	M	8	Most nuts, eggs, sesame (anaphylaxis) aspirin, penicillin, elastoplast, strawberries (allergy)	Yes	Face-to-face, online
14	F	10	Peanuts (avoids all nuts), allergic to animal dander	Yes	Face-to-face, online
14	M	13	Nuts and eggs	Yes	Face-to-face, online
15	F	2	Peanuts, most tree nuts	Yes	Face-to-face, online
12	F	<1	Eggs, all nuts, seeds, legumes, sesame, coconut, paprika	Yes	Face-to-face, online
13	F	3	Peanuts (animals)	Yes	Online
21	F	1	Peanuts (nut, pregabalin, gabapentin)	Yes	Online
20	F	2	Peanuts (avoids all nuts)	Yes	Online
12	F	9	Eggs, nuts, bananas, kiwi, latex	Yes	Online
21	F	3	Exercise induced anaphylaxis to wheat, barley, rye, oats, allergic to celery, walnuts, cod, wasp venom, milk, seafood	Yes	Online
16	F	6	Milk, eggs, nuts	Yes	Online
15	M	<1	Peanuts, almonds	Yes	Online
12	M	3	Nuts, seeds, banana, kiwi, eggs, peanuts	Yes	Face-to-face, online
15	M	5	Eggs, nuts, peanuts, wheat, gluten, most fruit and veg	Yes	Face-to-face
19	M	12	Nuts, fish, milk, peas, sesame, poppy seeds	Yes	Face-to-face, online
21	F	<1	Milk, peanuts, all nuts, protein PR10, various medications, type 1 latex allergy, dust mite, mould, hayfever	Yes	Online
14	M	10	Peanuts, raw eggs	Yes	Online



Figure 1. Geographic distribution of participants across UK

NB - there are only 15 locations on the map as some areas represent multiple participants

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Table 2. Mechanisms as to how resources provided by support groups improve self-care

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*"I think that made a massive difference with people sharing what they had been through with their anaphylaxis and how bad it can get, like with ITU and stuff. It made me think maybe I should carry my EpiPen with me everywhere"* (Female aged 21)

*"I just think it reinforces it so when you see posts you just ... like if there was any like ... if there was maybe a tiny bit of my mind thinking "Maybe today I will risk it and go out without my EpiPen" I would see this online and think "No." (Female aged 21)*

*"But it is quite good I think support groups have helped me from that point of view – to actually sort it out and take my EpiPens and things like that."* (Female aged 21)

*"Well I myself know the importance of always carrying it, but definitely reinforces it, because you hear all the other things that other people go through, all the things that can happen."* (Male aged 15)

*"Yeah well that is what I was doing beforehand, because to be honest with you before I joined these groups I didn't really kind of take my allergy seriously. I would go out and not take my EpiPen like ... I would eat anything. Because I didn't ... I just didn't really take it seriously."* (Female aged 20)

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Table 3. Practical aspects valued by members

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*“One group had run and it was things where there were hidden allergens like all the wheat in hair spray... I was like “Oh God” and it sounds like a lie now when I say it but it was there in black-and-white that I physically hadn’t looked. So it was stuff like that that I have found really helpful because I know without a support group I wouldn’t have found those links.” (Female aged 21)*

*“The main thing is like brands of foods – that is the main thing that I get from these groups anyway. But I have found so many foods I probably wouldn’t... I wouldn’t even think about checking or that I wouldn’t know that I could have, if it wasn’t for these Facebook groups.” (Female aged 15)*

*“They can correct you if you are wrong about something that you say. And I think it is really good because it is reassuring knowing someone professional is there who knows all about it.” (Female aged 12)*

*“I think just the fact as well that they do like seasonal things. So they can help with like Christmas stuff and Halloween and Easter. So they change it up each season and it is like specific to that. So obviously when it is Christmas everyone gives each other ideas on like Christmas chocolates that are safe to eat or you know... because it is quite hard. So I think that is really good.” (Female aged 20)*

*“So I can eat new things. Like at Christmas time we could eat like these new chocolate mousse that we never knew we could eat before. And we found it on there – on the website.” (Female aged 12)*

*“Their Facebook page sort of shows you new and interesting articles about how allergies are being handled in different situations or new things on different developments and stuff. So it is like a way to keep up with everything that is happening and how it might affect you and your friends and your family and stuff like that” (Female age 15)*

*“The texts are really, really helpful because if you have bought something and you think it is fine, I think you are aware that you can’t eat it, because otherwise you will have an allergic reaction, if you are not aware of it.” (Female aged 12)*

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Table 4. Recommendations for improving awareness and uptake of support groups

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*“That video that the Anaphylactic Campaign did about that girl ... and she was at the park and then she kissed a boy and then she like died. That was really like good – that was a really good video. I think maybe like show that in schools and then have like an allergy thing”* (Female aged 15)

*“The videos and stuff, they were cool because they raise awareness. So I think you just need to educate teenagers more on what allergies are and how they can affect your life. And then they will probably feel more open to talk about it or find other ways to deal with it”* (Female aged 15)

*“I think advertising on sort of social media and stuff is a big thing for it because everyone my age and younger is on social media; or for adverts during TV because they watch TV on catch-up on their laptops or whatever”* (Female aged 21)

*“I think social media. Because everyone seems to be on it these days... Maybe just reach out to the people who have like emails, who are members of the Anaphylaxis Campaign. If they do have kids maybe email them (chuckle) to join or something like that and just to get them involved, because it might actually help ... well they do help quite a lot. So they might be quite happy about that”* (Female aged 15)

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Table 5. Recommendations for improved support for young people

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*"I mean my Mum is always like looking into new support groups and stuff. Because it is something that I probably would like to be in, we are just trying to find the right one at the moment."* (Male aged 14)

*"In more areas, because there are only a few once a year but they are not in the same place they are in ... all dotted around the country"* (Female aged 12)

*"I think the Anaphylaxis Campaign does a very good job at what it does. Except I would like their workshops because I thought they helped a lot of people. And they replaced them with the videos which I don't think are as effective."* (Male aged 16)

*"I reckon something like similar to the last one – maybe a bit more fun because that was very informative."* (Female aged 15)

*"Maybe like workshops on Saturdays for children: which is like a club so do like activities like just having fun club where you can get to know each other and make friends. But then you can also like talk to each other about your condition. I think it is quite nice when you know someone else who is there in your situation."* (Female aged 12)

*"I have never really known not being a member... So I can't pin point the exact benefits apart from that I just know all about my allergies... Which I assume that if you weren't you probably would know half as much, which means that you wouldn't be as safe."* (Male aged 16)

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